



PUBLIC HEALTH INFORMATION SHARING Resource

Laws that Impact Individually Identifiable Personal or Health Information

Resources regarding selected laws that impact the collection, use, sharing and protection of individually identifiable personal or health information for public health purposes:

Federal and State Privacy Laws

George Washington University's Hirsh Health Law and Policy Program recently launched an online guide to federal and state laws governing access, use, release and publication of health information: Health Information and the Law at <http://www.healthinfolaw.org>.

HIPAA Privacy Rule

The U.S. Department of Health and Human Services, Office for Civil Rights, hosts a comprehensive website regarding the HIPAA Privacy Rule that includes many useful guidance documents and tools related to HIPAA applicability and exceptions. The website is at <http://www.hhs.gov/ocr/privacy>.

- Materials focused on public health can be found here: <http://www.hhs.gov/ocr/privacy/hipaa/understanding/special/publichealth/index.html>.
- See especially, "HIPAA Privacy Rule and Public Health, Guidance from CDC and the U.S. Department of Health and Human Services" at <http://www.cdc.gov/mmwr/preview/mmwrhtml/m2e411a1.htm>.

Health Information Technology for Economic and Clinical Health (HITECH) Act

- The Centers for Disease Control provides resources regarding "meaningful use" and public health applications at <http://www.cdc.gov/ehrmeaningfuluse>.
- The Office of National Coordinator for Health Information Technology (ONC) provides resources regarding "meaningful use" at <http://www.healthit.gov/policy-researchers-implementers/meaningful-use>. The ONC, located within HHS, has a portal for information and resources about electronic health information and health information exchange at <http://www.healthit.gov>. The ONC is the principal federal entity charged with coordination of nationwide efforts to support adoption of health information technology and development of health information exchange.



Family Educational Rights and Privacy Act (FERPA)

FERPA regulations, guidance, training materials and other information can be found on the websites of the U.S. Department of Education <http://www2.ed.gov/policy/gen/reg/ferpa/index.html>, and its Family Policy Compliance Office <http://www2.ed.gov/policy/gen/guid/fpco/index.html>.

Federal Privacy Act

The U.S. Department of Justice provides a comprehensive website regarding the federal Privacy Act at <http://www.justice.gov/opcl/privacyact1974.htm>.

Federal Freedom of Information Act

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The U.S. Department of Justice provides a government-wide portal for the Freedom of Information Act at <http://www.foia.gov>. In addition to information about the federal FOIA, the website covers the federal government's "open government initiative" and includes a tool to search across all federal government websites at once, including the websites of the smaller offices and components that make up these departments and agencies, to see what is already available without the need to file a FOIA request.

State Freedom of Information or Public/Open Records Acts

The Reporters Committee for Freedom of the Press provides an Open Government Guide at <http://www.rcfp.org/open-government-guide>, which is a complete compendium of information on every state's open records and open meetings laws. Each state's section is arranged according to a standard outline, making it easy to compare laws in various states.

The State of Health Privacy (2nd Edition)

A Survey of State Health Privacy Laws, organized alphabetically by state.

- Vol 1: <http://ihcrp.georgetown.edu/privacy/pdfs/statereport1.pdf>
- Vol 2: <http://ihcrp.georgetown.edu/privacy/pdfs/statereport1.pdf>

This survey was completed in 2002 so will need to identify any updates for individual states.

Guidance on the release of information concerning deaths, epidemics or emerging diseases

This guidance – at <http://www.healthjournalism.org/secondarypage-details.php?id=965> – was developed by the Association of State and Territorial Health Officials (ASTHO), the National Association of County and City Health Officials (NACCHO) and the Association of Health Care Journalists (AHCJ) to address the balance between informing the public and protecting privacy.

Protection of human research subjects

The U.S. Department of Health and Human Services Office of Human Research Protections provides a comprehensive website regarding federal laws to protect human research subjects at <http://www.hhs.gov/ohrp>. The use of identifiable public health data for research may be subject to these federal laws.

Public health practice, which includes epidemiological investigations, surveillance, programmatic evaluations and clinical care for the population, is not research. Resources that provide assistance in distinguishing public health practice from research include:

- The CDC's "Distinguishing Public Health Research and Public Health Nonresearch" at <http://www.cdc.gov/od/science/integrity/docs/cdc-policy-distinguishing-public-health-research-nonresearch.pdf>
- The Council of State and Territorial Epidemiologists report "Public Health Practice vs. Research" at <http://www.cste.org/pdffiles/newpdf/CSTEPHResRptHodgeFinal.5.24.04.pdf>.



Current and Emerging Issues Regarding Public Health Collection, Use and Sharing of Information

Links to information and journal articles on selected current and emerging information sharing issues:

Public health as a data contributor to fusion centers to prevent terrorism

- U.S. Department of Homeland Security's Fusion Center Web Page at http://www.dhs.gov/files/programs/gc_1156877184684.shtm.
- Health Security: Public Health and Medical Integration for Fusion Centers downloadable at <http://www.it.ojp.gov/default.aspx?area=nationalInitiatives&page=1181>.

Public health data collection and use: public health, privacy, and autonomy issues

- Fred H. Cate, The Autonomy Trap, The Privacy Symposium Cambridge, MA, Aug. 24, 2007. Available at <http://www.fredhcate.com/Publications/The%20Autonomy%20Trap.revised.pdf>.
- Amy L Fairchild, et al., Public Goods, Private Data: HIV and the History, Ethics, and Uses of Identifiable Public Health Information. Available at: http://papers.ssrn.com/sol3/papers.cfm?abstract_id=1421899.
- Wendy K. Mariner, Mission Creep: Public Health Surveillance and Medical Privacy, 87 BURL 347, 355. 96 GeorgLJ 705. Available at <http://www.bu.edu/law/central/jd/organizations/journals/bulr/volume87n2/documents/MARINERv.2.pdf>.
- Jean O'Connor, Informational Privacy Protections: Do State Laws Offer Public Health Leaders the Flexibility They Need? Doctoral dissertation submitted to the faculty of the University of North Carolina at Chapel Hill, available at http://www.sph.unc.edu/images/stories/academic_programs/hpaa/documents/oconnor.pdf.

Providing newborn screening specimens for research

- Michelle Lewis, et al., State Laws Regarding the Retention and Use of Residual Newborn Screening, Pediatrics, originally published online March 28, 2011 <http://pediatrics.aappublications.org/content/early/2011/03/28/peds.2010-1468.full.pdf+html>.
- Providing Newborn Screening Specimens for Research: Legal Issues Faced by State Health Departments. Webinar series sponsored by the Network for Public Health Law, Newborn Screening Translational Research Network, Association of Public Health Laboratories, and National Newborn Screening and Genetics Resource Center. http://www.networkforphl.org/newborn_screening.

Access to data in electronic health records to benefit population health and health care

Sharona Hoffman and Andy Podgurski, Balancing Privacy, Autonomy, and Scientific Needs in Electronic Health Records Research (April 12, 2012), Southern Methodist University Law Review, Vol. 65, p. 85, 2012; Case Legal Studies Research Paper No. 2011-22. Available at SSRN: <http://ssrn.com/abstract=1923187>.

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SUPPORTERS

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